

## CHAPTER VI

### Infants

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In 2002, 20,970 infants were born in Idaho (Idaho Department of Health and Welfare, 2004a) with their families and health care providers hopeful that each infant would arrive at term, of normal weight, without preventable defects and subsequently screened for potential problems. The first year of the infant's life is a time of rapid growth and development, and what happens during this period matters a great deal because it sets either a sturdy or a fragile stage for what follows in the life of the child and future adult (National Research Council and Institute of Medicine, 2000).

This section of the assessment describes the health and well-being of Idaho's infants from birth to 1 year of age.

#### A. Characteristics of Births in Idaho

The birth rate (total number of births per 100,000 people based on 2004 population estimates) for the entire State was 15.8 in 2002 and increased to 16 in 2003 with 21,802 births reported in the State. In comparison, the U.S. birth rate was reported as 13.9 for 2002 and as 14.1 for 2003. Despite a nationwide decline in the number of births over the past decade, a number of States, including Idaho, are showing significant increases (National Center for Health Statistics, Trends in Characteristics of Births by State, 2004). Idaho is also reporting changes in the race and ethnicity distribution of infants born in the State, as displayed in Table VI-1.

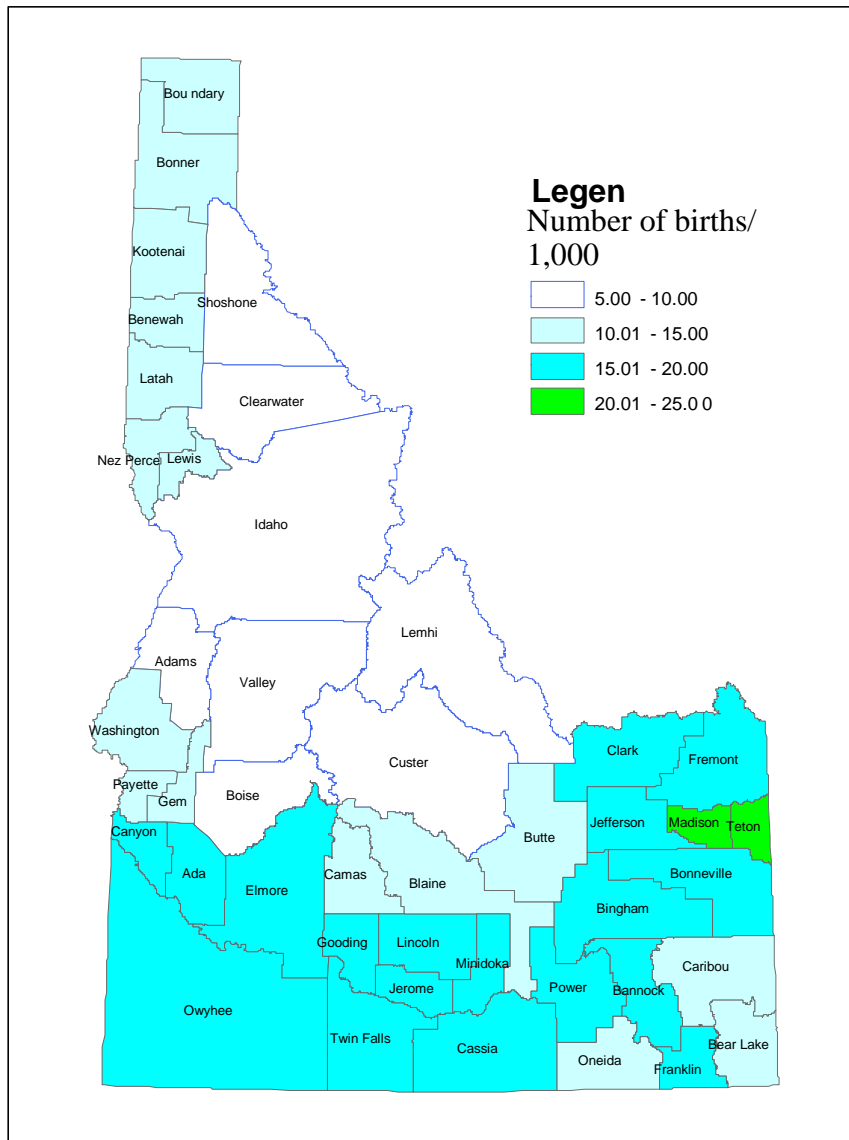
<b>Table VI-1. Idaho Resident Live Births by Race and Ethnicity, 2000-2002</b>						
	Idaho Total	Non- Hispanic White	American Indian	Asian Pacific	Non- Hispanic Black	Hispanic
2002	20,970	17,074 (81.4%)	377 (1.8%)	339 (1.6%)	100 (.5%)	2,788 (13.3%)
2001	20,688	16,855 (81.5%)	360 (1.7%)	298 (1.4%)	78 (.4%)	2,753 (13.3%)
2000	20,336	17,021 (83.7%)	288 (1.4%)	298 (1.4%)	74 (.4%)	2,599 (12.8%)

Source: Sutton and Mathews, 2004

The southern part of the State is reporting the most births in the State and this is reflective of the growing population residing in this area.

Birth rates by county are displayed in Figure VI-1:

### Live Birth Rates (2001 -2003)



**Figure VI-1: Live Birth Rates, 2001-2003**

Source: Idaho Department of Health and Welfare, 2004b

Counties reporting the highest birth rates include Madison with 20.8, Teton with 20.4, Canyon with 19.7, and Jefferson with 18.1. Of the 63,453 live births between 2000 and 2002, 8,478 or 13.4 percent of all births were reported as Hispanic. Counties with the highest Hispanic birth rates include Valley with 38.8, Camas with 35.3, Bear Lake with 35.3, Blaine with 31.7, Lincoln

with 30.3, and Payette with 30 (Idaho Department of Health and Welfare, September 2004). A significant percentage of Idaho births are occurring to mothers of Hispanic origin requiring the perinatal health system to be sensitive to the special needs and concern of this population in terms of language, culture, and health-seeking behaviors.

## Characteristics of Birthplace

- *Site of Births and Birth Attendant*

The majority of births occurred in a hospital setting and were attended by a physician (19,774), others by a certified nurse-midwife (782), and still others by a lay midwife (272). In addition, 50 births were attended by a naturopath and 42 by a nurse. In 2002, 34.2 percent of total live births were financed by Medicaid (Kaiser State Health Facts, 2000).

<b>Table VI-2. Infants Place of Birth in Idaho - 2002</b>		
<b>Place of Birth</b>	<b>Number</b>	<b>Percent of Total Births</b>
Hospital	20,470	97.6
Freestanding Birthing Center	145	0.7
Clinic/Doctor's Office	1	0.0
Home	351	1.7
Other	2	0.0
Not reported	4	0.0
<b>Total Births</b>	<b>20, 973</b>	<b>100%</b>

Source: Idaho Department of Health and Welfare, 2004a

While most Idaho infants are delivered in a hospital, Idaho does report a higher rate of home births, 1.7, than the national rate of 0.6 (Martin et al., 2003). While the number of births attended by a midwife is relatively small in Idaho, key-informant interviewees and women participating in the focus groups indicated that women are interested in having birthing site and attendant options available to them.

The State nurse-practice act was changed in 1998 to permit the practice of nurse-midwifery in Idaho. There are five CNM practice sites in Idaho authorized for delivery services. These are located in Coeur d'Alene, Boise, Jerome, Rexburg, and Pocatello. Although CNMs may legally conduct a home delivery within a circumscribed protocol and with appropriate physician backup, none do so in Idaho.

Another classification of midwife, called direct-entry midwives, also practices in Idaho. Non-nurse-midwives practicing in Idaho may be certified by the North American Registry of Midwives (NARM). Midwives need documentation of compliance with practice requirements and the successful completion of an examination. This permits these midwives to identify themselves as certified professional midwives (CPMs). While these midwives are licensed in several States, they are not licensed in Idaho.

A total of 496 births or 2.4 percent of total births occur outside the hospital, necessitating the need for a system that ensures that the infants are appropriately screened for metabolic conditions and hearing loss and have access to a medical home.

<b>Table VI-3. Number of Out-of-hospital Births, 2002</b>			
	<b>Freestanding Birthing Center</b>	<b>Home Birth</b>	<b>Percent of Out- of-hospital Births by District</b>
District I	2	91	4
District II	1	49	4
District III	114	81	5.2
District IV	27	52	1.4
District V	-	34	1.3
District VI	-	17	.6
District VII	1	27	.9
Total	145	351	2.4

Source: IDHW Bureau of Health Policy and Vital Statistics, 2004a

- Method of Delivery.** Overall, Idaho ranks lower than most other States for rates of births by cesarean delivery, with a 2002 rate of 19.7 and a 2003 rate of 21.2 compared to national rates of 26.1 and 27.6, respectively. A somewhat higher rate is reported for Hispanic mothers, with a 2002 rate of 20.5 and 2003 rate of 21.6 (Hamilton et al., 2004). The March of Dimes (2004a) reports that in Idaho in 2002, the rate of primary cesarean deliveries was 12.8 per 100 live births to women who have not had a previous cesarean delivery. The rate of vaginal births after a previous cesarean was 17.4 per 100 live births to women who have had a previous cesarean delivery compared with a U.S. rate of 12.6 (March of Dimes, 2004b).

## Summary

Idaho reported 20,970 births in 2002 and experienced a higher birth rate (15.8) than the national rate of 13.9, with the birthrate continuing to grow in 2003. Most of the births were to White mothers, with a number of mothers indicating Hispanic ethnicity. Several counties reported birth rates above the statewide average; these included Madison, Teton, Canyon, and Jefferson. Counties, with high rates of birth to Hispanic mothers included Valley, Camas, Bear Lake, and Blaine. A high percentage of births were to American Indian, Black, and Hispanic mothers who were unmarried. Idaho ranks 28<sup>th</sup> among the States with a 2002 teen birth rate of 39.1. Higher teen birth rates were reported for American Indian, Black, and Hispanic mothers.

Although most births in Idaho occur in a hospital setting, the State does report a higher rate of home births than the national rate. A number of births in the State were attended by midwives. Idaho ranks in the 10 lowest for rates of birth by cesarean section delivery.

We now have a picture of the resident live births in Idaho that includes the number of births and birth rates. Within the context of these findings, the discussion now turns to a review of birth outcomes. Data is presented for each outcome along with information about current programs and services related to the outcome.

## B. Infant Outcomes Examined

Four outcomes have been selected for indepth examination of the Idaho infant population. Achieving these outcomes will help to ensure that infants have the best start in life enabling them to reach their full potential and that their families are provided the support they to help their infants grow and develop appropriately.

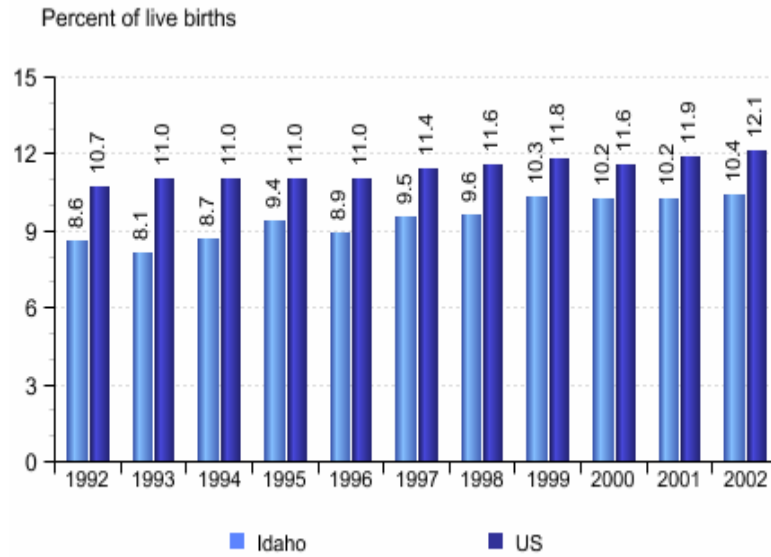
<b>Table VI-5. Idaho Infant Outcomes</b>
Infants are born at term, of normal weight, without preventable congenital defects and are appropriately screened for potential problems.
VLBW/preterm babies are born in facilities equipped to care for them.
Infants are welcomed into a family, a home, and a community that is prepared to care for them.
Infants appropriately receive ongoing comprehensive preventive and primary care.

### **1. *Infants are born at term, of normal weight, without preventable congenital defects and are appropriately screened for potential problems.***

Unfortunately, not all infants are born full term, at normal weight, and without preventable anomalies, and an increasing number of infants are born prematurely or at LBW. Classifying births by gestation and birth weight is useful because this characteristic often corresponds to clinical morbidities or illnesses that affect the health of the infants and their subsequent growth, development, and well-being.

While both premature and LBW births are described individually, it is useful to consider the parallel increase in the trends for both premature and LBW rates over time. Trends for preterm and LBW births by percent of live births for the years 1992 through 2002 are displayed in the following two graphs.

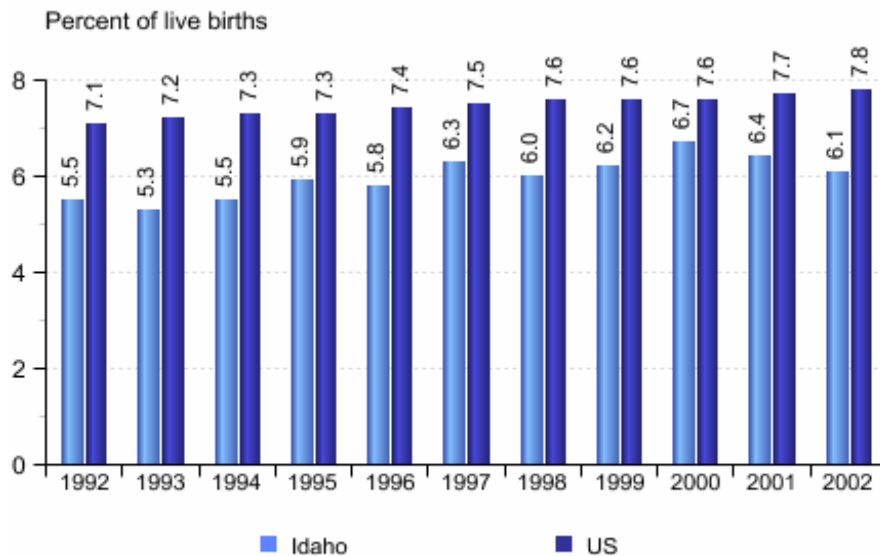
**Figure VI-2: Preterm Births: Idaho and U.S., 1992-2002**



Copyright March of Dimes, 2004

Note: Data is from the National Center for Health Statistics, final natality data.  
Source: March of Dimes, 2004c

**Figure VI-3: LBW Births: Idaho, 1992-2002**



Copyright March of Dimes, 2004

Note: Data is from the National Center for Health Statistics, final natality data.  
Source: March of Dimes, 2004d

Over this 10-year period, Idaho has consistently reported lower percentages of both preterm and LBW births than the U.S. percentages (Figure VI-3). However, the percentage of preterm live births in Idaho has fairly consistently increased over time, reaching 10.4 percent in 2002. It is important to note that the Healthy People 2010 goal for preterm births is to reduce to no more than 7.6 percent of live births and to reduce the LBW rate to no more than 5 percent of live births (U.S. Department of Health and Human Services, 2000). Idaho is coming much closer to the national goal for LBW births than for premature births (Figure VI-4).

LBW and premature births are both important public health problems due to the seriousness of acute complications and long-term consequences to the infant, the infant's family, and society as a whole. The March of Dimes (2005) reports that more than 60 percent of all infants born in the United States under 2,500 grams are also preterm. Compared with full-term LBW babies, preterm LBW infants are at greater risk of morbidity, mortality, and disability.

While the causes of LBW and preterm birth may be different in some cases and are not well-known, there is significant overlap within these populations of infants. Table VI-6 displays the Idaho live births by weight and gestational age for a 3-year period (2001-2003). Reviewing data over a period of 3 years provides a truer picture of outcomes than the review of a single year, in which some unusual events may produce an atypical picture of outcomes.

<b>Table VI-6.</b> <b>Idaho Resident Live Births by Weight and Gestational Age 2001 -2003</b>				
	Birth Weight			
<b>Total Idaho Births:</b> 63,453 (2001-2003)	< 1,500 Grams (VLBW)	1,500-2,499 Grams (LBW)	2,500-3,999 Grams (Normal Weight)	4,000-4,499 Grams (High Birth Weight)
	629 (1.0%)	3,408 (5.4%)	53,826 (84.9%)	4,764 (7.5%)
	<i>Gestational Age*</i>			
	< 32 Weeks (Very Preterm)	32-36 Weeks (Preterm)	37+ Weeks (Normal Term)	
	880 (1.4%)	5,675 (9.0%)	56,699 (89.6%)	
* Gestation is based on the interval between the date of the mother's last menstrual cycle (LMC) and the date of birth.				

Source: Idaho Department of Health and Welfare, 2004b

Further classification by race and ethnic group offers additional insights. Idaho rates for birth weight and preterm birth by race or ethnicity are displayed in Table VI-7. The table includes data for VLBW infants and very preterm infants as defined in Table VI-6.

<b>Table VI-7. Birth Weight and Preterm Births by Race and Ethnicity, 2001-2003, by Percentage of Live Births for Idaho</b>						
<b>Population Groups:</b>	<b>All Races and Ethnicities</b>	<b>Am. Indian</b>	<b>Hispanic</b>	<b>Black</b>	<b>Asian</b>	<b>White</b>
<b>% Preterm Births:</b>						
Idaho	10.4	11.7	11.3	11.6	10.3	10.3
<b>% LBW*</b>						
Idaho	6.4	5.9	6.7	10.2	6.5	6.4

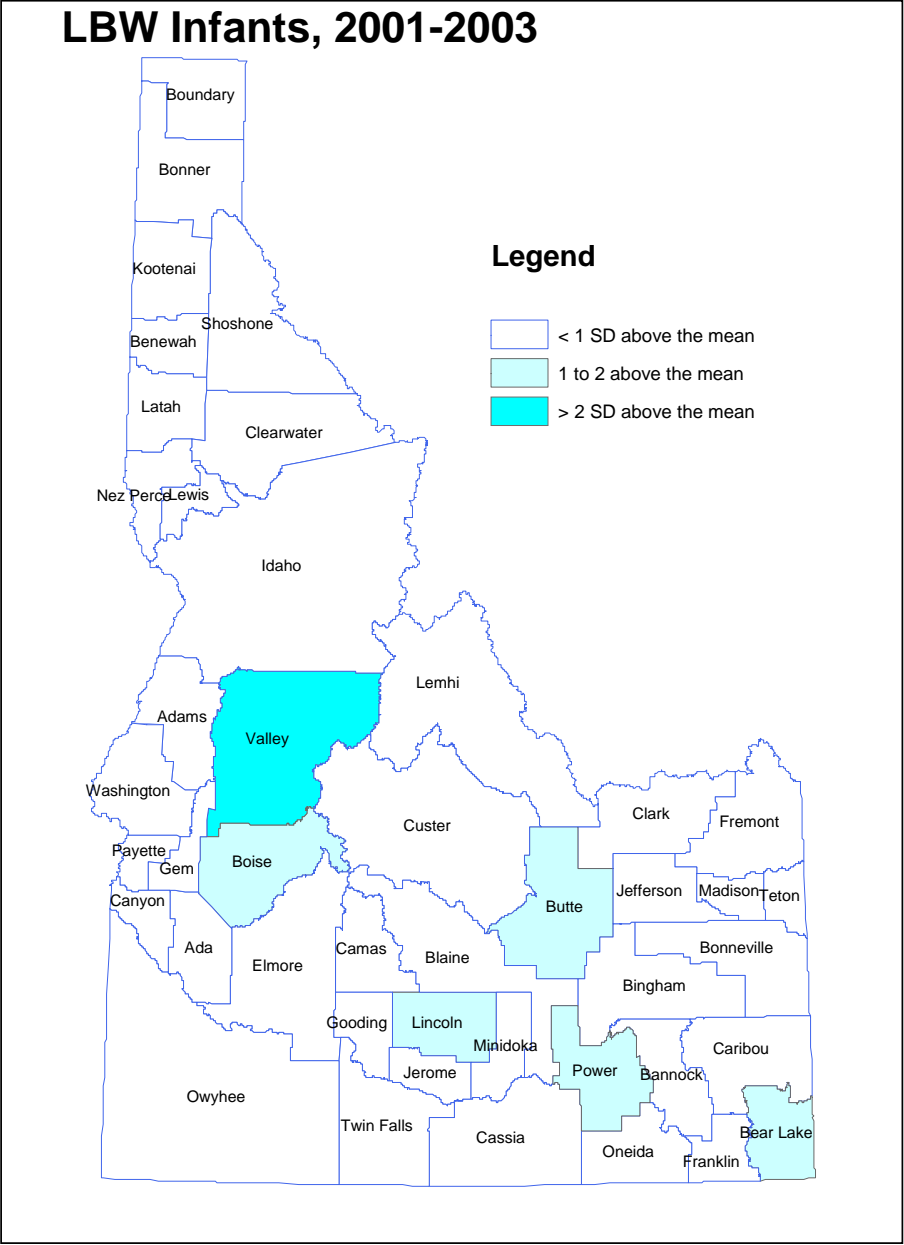
\*Less than 2,500 grams

Source: Idaho Department of Health and Welfare, 2004b

When the percentage of births in Idaho is reviewed by specific race and ethnicity, important differences are revealed, with a higher percentage of premature births reported for American Indian and Black infants.

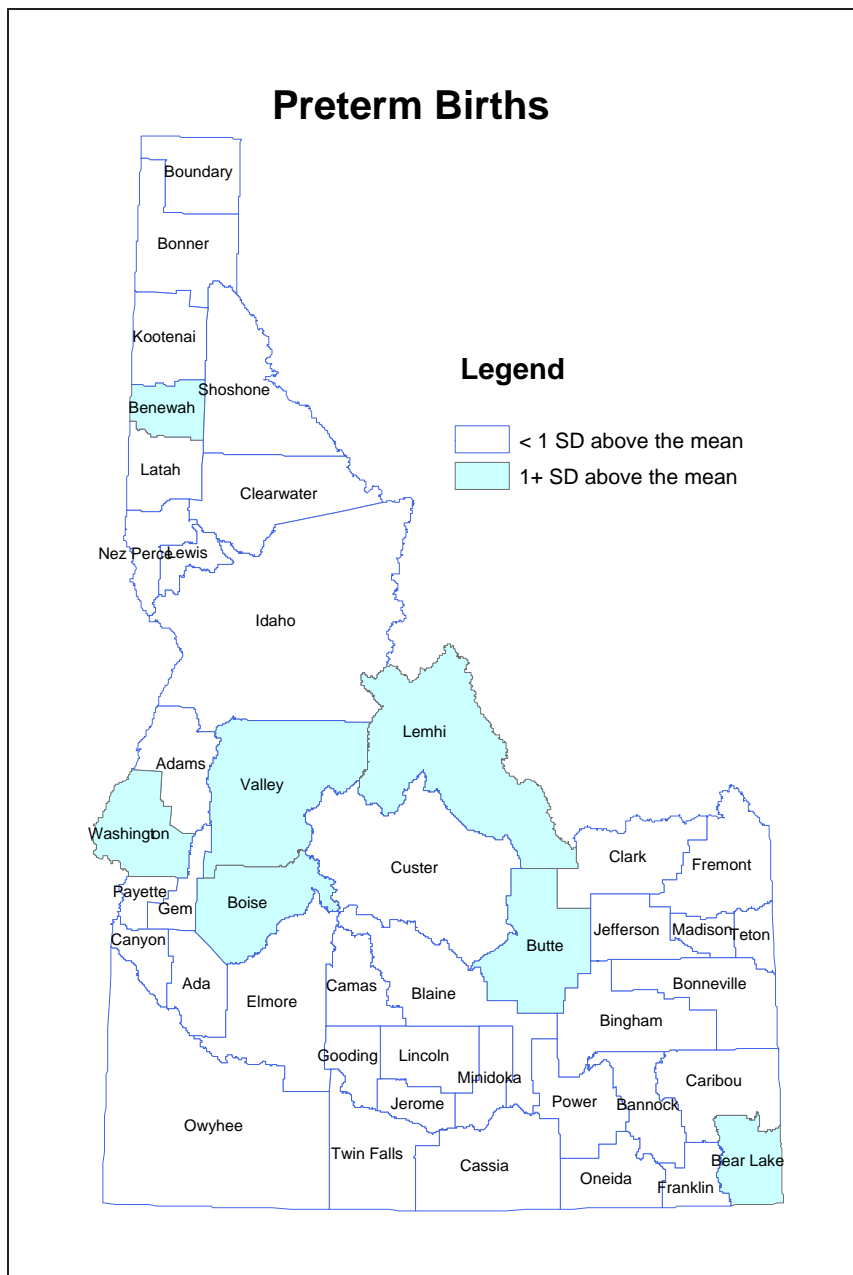
It is also useful to review data at the county level. County-level data are displayed in a series of maps, presented here by a standardized measure of how much the county-level data differ from the mean (or average) of data from all counties. This standardized measure is known as the standard deviation. Therefore, counties with a very high rate of LBW births are identified as 2 plus standard deviations from the mean of the rates of LBW births for all counties. Counties with a high rate of LBWs have a standard deviation of 1-2 from the mean of the rates for all counties. Counties with low rates of LBW births are those with standard deviations of 1 or less from the mean of all counties. See Figure VI-4.





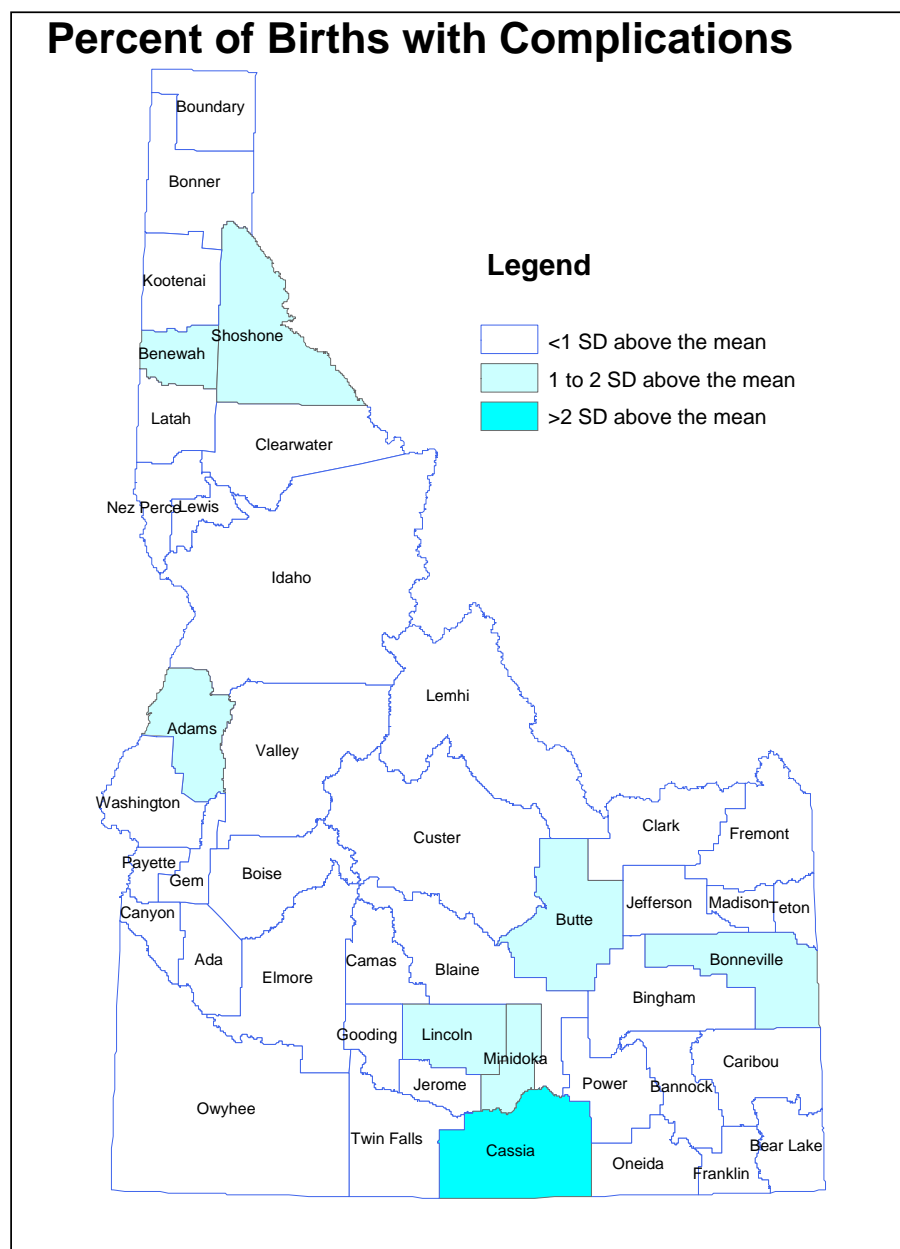
**Figure VI-4: Low Birth Weight Infants, 2001-2003**

Source: Idaho Department of Health and Welfare, 2004b



**Figure VI-5: Preterm Births, 2001-2003**  
 Source: Idaho Department of Health and Welfare, 2004b

Figure VI-6: Percent of Births with Complications (certain conditions originating in the perinatal period—ICD codes 760-779), 2001-2003 displays county-specific infant mortality data in the same fashion as the other maps.



**Figure VI-6: Percent of Births with Complications, 2001-2003**

Source: Idaho Department of Health and Welfare, 2004b

## Infant Deaths

Infant mortality is defined as death occurring during the first year of life. Infant deaths can be classified further into neonatal (0-27 days) and postneonatal (28-365 days) periods.

Neonatal mortality is typically associated with events surrounding the prenatal period and the delivery, whereas postneonatal deaths are more likely to be associated with conditions or events that arise after the delivery and may reflect environmental factors. Neonatal and postneonatal mortality are examined differently, as the primary prevention opportunities for each period differ in accordance with the period in which the death occurred. For example, VLBW-related deaths can be prevented best by addressing maternal health issues and by preventing and treating prematurity. Neonatal deaths can best be prevented by providing optimal newborn care and postneonatal deaths by improving infant care.

The following table displays the number and rate of infant deaths in Idaho for the year 2002 by neonatal and postneonatal periods by district.

<b>Table VI-8.</b>							
<b>Idaho Resident Infant Deaths 2002 Data</b>							
	<b>Total Live Births</b>	<b>Infant Deaths All Races and Ethnic Groups</b>					
		<b>Total</b>		<b>Neonatal</b>		<b>Postneonatal</b>	
		<b>Number</b>	<b>Rate</b>	<b>Number</b>	<b>Rate</b>	<b>Number</b>	<b>Rate</b>
Districts							
I	2,226	14	6.3	9	4.0	5	2.2
II	1,189	3	2.5	2	1.7	1	0.8
III	3,715	27	7.3	20	5.4	7	1.9
IV	5,563	35	6.3	24	4.3	11	2.0
V	2,550	17	6.7	8	3.1	9	3.5
VI	2,789	16	5.7	8	2.9	8	2.9
VII	2,941	15	5.1	13	4.4	2	0.7
<b>Idaho</b>	<b>20,973</b>	<b>127</b>	<b>6.1</b>	<b>84</b>	<b>4.0</b>	<b>43</b>	<b>2.1</b>

\*Per 1,000 deaths

Source: Idaho Department of Health and Welfare, 2004a

While Idaho reports virtually the same neonatal mortality rate as the United States as a whole, the death rate for non-Hispanic White infants is higher in Idaho than in the United States as a whole. The rate of deaths for infants in the neonatal period is significantly higher for Idaho's Hispanic neonates than the rate for the State as a whole or the U.S. Hispanic rate.

<b>Table VI-9. Neonatal Mortality Rates* of Non-Hispanic White and Hispanic Infants, Idaho and U.S., 2000-2002</b>		
	<b>U.S.</b>	<b>Idaho</b>
All Races	4.6	4.5
Non-Hispanic White	3.8	4.1
Hispanic**	3.8	6.8

\*Data are based on linked birth and death certificates for infants.

\*\* Infants of Hispanic origin could be any race.

Source: National Center for Health Statistics, 2004

Again, while overall Idaho rates seem to compare favorably with overall U.S. rates, when infant deaths are reviewed by specific race and ethnic groups, a very different picture emerges.

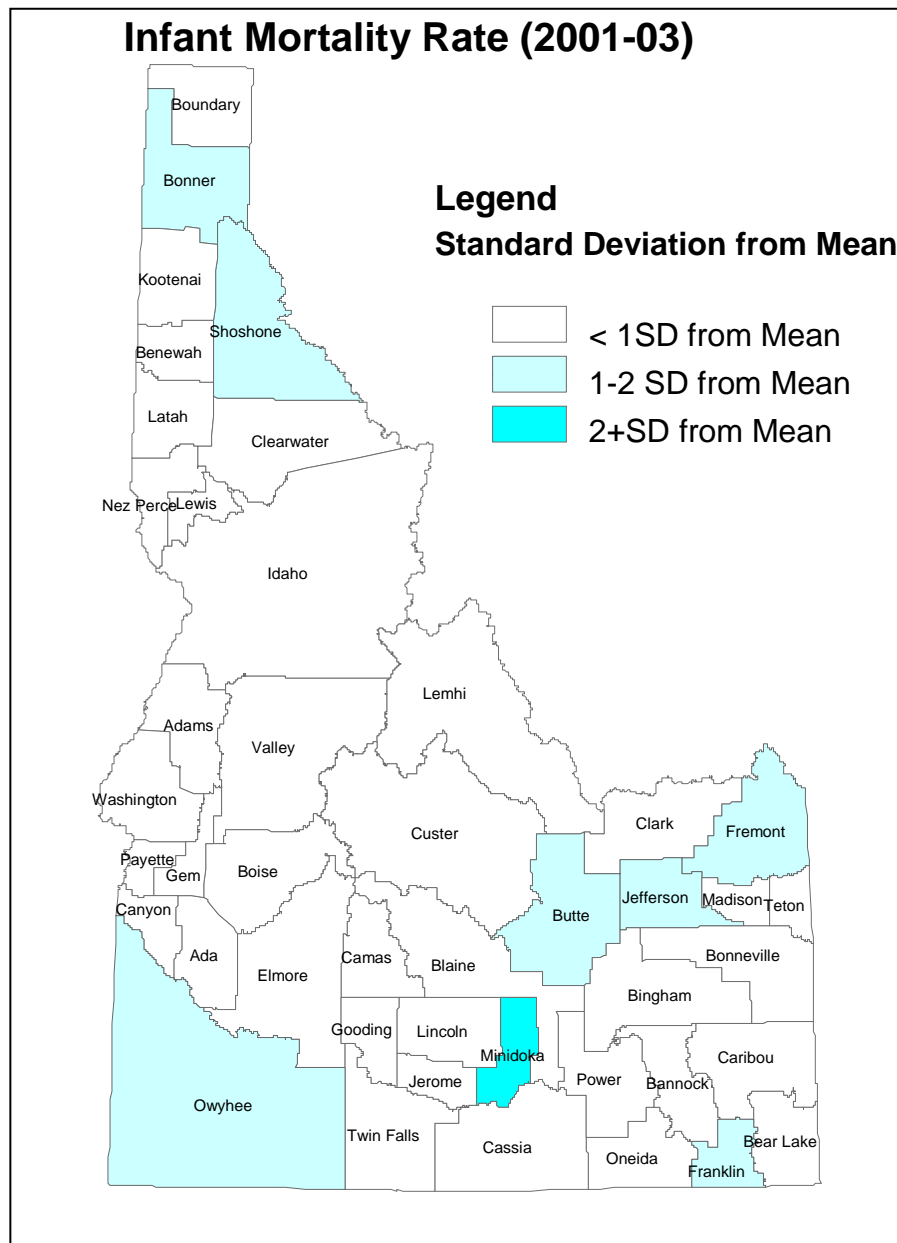
<b>Table VI-10. Infant Mortality Rates* of Non-Hispanic White and Hispanic Infants Idaho and US 2000-2002</b>		
	<b>US</b>	<b>Idaho</b>
All races	6.9	6.6
Non-Hispanic White Infants	5.7	6.2
Hispanic Infants**	5.5	8.8

\*Data are based on linked birth and death certificates for infants.

\*\* Infants of Hispanic origin can be of any race.

Source: National Center for Health Statistics, 2004

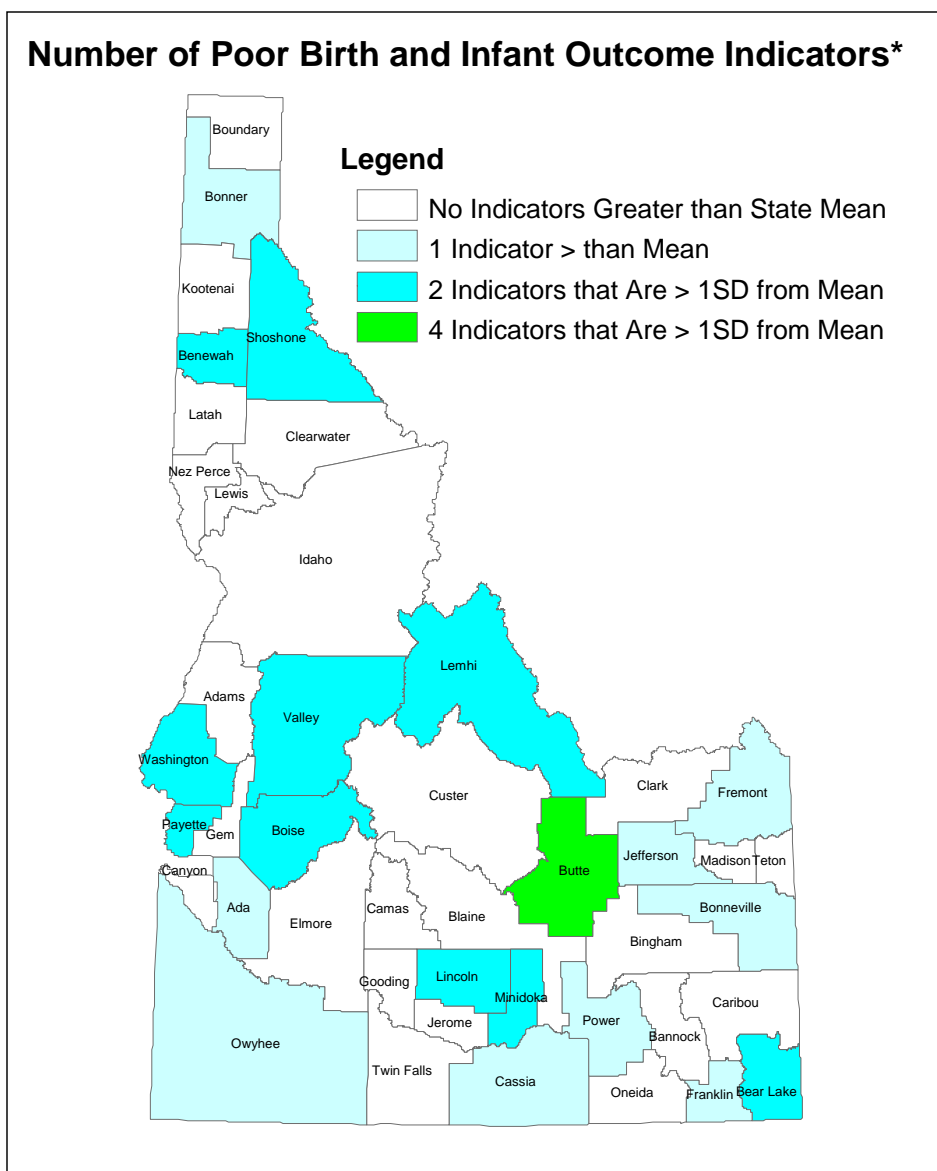
Overall, Idaho reports higher infant mortality rates for non-Hispanic White infants than the national rate and significantly higher rates for Hispanic infants.



**Figure VI-7: Infant Mortality Rate, 2001-2003**

Source: Idaho Department of Health and Welfare, 2004b

Finally, Figure VI-8: Number of Poor Birth Outcome Indicators per County displays counties by their number of poor birth outcome indicators. Indicators include the incidence of some degree higher than the State averages for infant mortality, premature and LBW births, and births with complications. Counties are identified with very high rates (4 indicators), high rates (2 indicators), and above average rates (1 indicator). None of the counties had 3 indicators.



**Figure VI-8: Number of Poor Birth and Infant Outcome Indicators**

\*ID Department of Health and Welfare Statistics. Indicators include high infant mortality rate per 1,000 (2001-03), high percentage of preterm births (2001-03), high percentage of LBW births (2001-03), and high percentage of live births with complications.

Source: Idaho Department of Health and Welfare, 2004b

As noted previously, counties with the highest Hispanic birth rates include Valley with 38.8, Camas with 35.3, Bear Lake with 35.3, Blaine with 31.7, Lincoln with 30.3, and Payette with 30 (Idaho Department of Health and Welfare, 2004a).

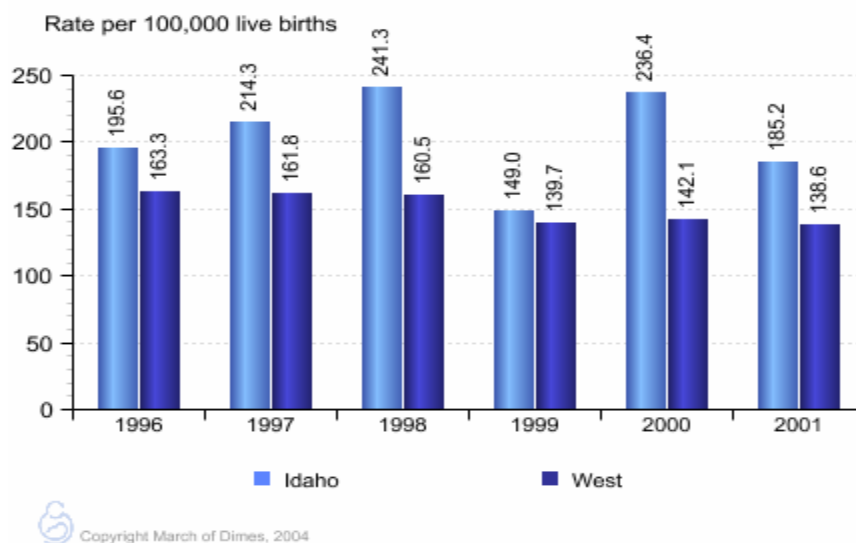
### What are the Causes of Death for Idaho Infants?

**Birth Defects/Congenital Anomalies.** A birth defect is an abnormality of structure, function, or body metabolism present at birth that results in physical or mental disability and may be fatal.

The general term “birth defect” may take on a variety of meanings depending on the context in which it is used. “Congenital abnormality,” “congenital anomaly,” and “congenital malformation” are terms often used as synonyms for “birth defect.” The term “congenital anomalies” is used in a revised ICD-10 code definition that includes a variety of congenital malformations, deformities, and abnormalities.

According to the IDHW Bureau of Health Policy and Vital Statistics, birth defects are the leading cause of infant mortality in the State, accounting for 1 of 3 or 30.7 percent of all infant deaths in Idaho in 2002 (Idaho Department of Health and Welfare, 2004a). According to the March of Dimes, the national rate of infant deaths attributed to birth defects is 1 in 5. The causes of about 60 percent of birth defects are currently unknown. Genetics, environmental factors, medications, and personal behavior can cause or contribute to birth defects (March of Dimes, 2004e).

While the western States generally have higher rates of infant deaths related to birth defects, Idaho ranks higher than the rest of these States on this indicator (Figure VI-9). The following graph displays the rate of infant deaths attributed to birth defects per 100,000 births for Idaho and other western States from 1996 to 2001.



**Figure VI-9: Infant Deaths Due to Birth Defects, Idaho and West\*, 1996-2001**

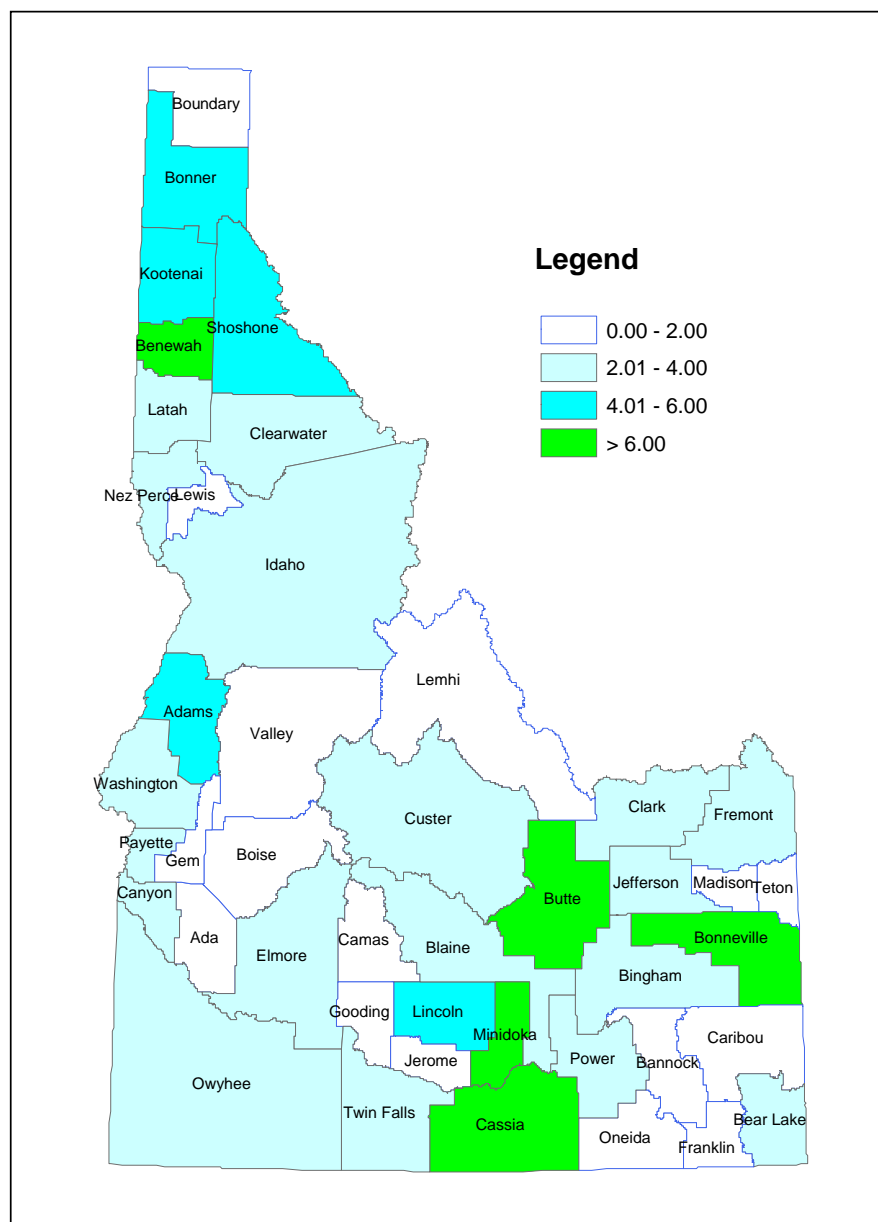
\*AK, AZ, CA, CO, HI, ID, MT, NV, NM, OR, UT, WA, WY

Source: March of Dimes, 2004f

The following Figure VI-10 displays the percent of congenital abnormalities per 1,000 live births by county.



## Percent of Live Births with Congenital Abnormalities



**Figure VI-10: Percent of Live Births with Congenital Abnormalities**

Source: IDHW Bureau of Health Policy and Vital Statistics, 2004

**Other causes of infant deaths.** Fifty-one (51) infant deaths were reported in 2002 under the general infant death category and were attributed to conditions that originated in the perinatal period such as LBW and infections. In the neonatal period, the second leading cause of infant death was reported as Sudden Infant Death Syndrome (SIDS). The exact causes of 36 or 28.5 percent (includes deaths reported as SIDS) of infant deaths are not reported and listed as “other causes.” Table 12 displays the causes of infant deaths.

<b>Table VI-11. Causes of Idaho Infant Death by Neonatal and Postneonatal Periods - 2002</b>						
	<b>Total</b>		<b>Neonatal</b>		<b>Postneonatal</b>	
<b>Cause of Death**</b>	<b>Number</b>	<b>Rate</b>	<b>Number</b>	<b>Rate</b>	<b>Number</b>	<b>Rate</b>
All causes	126	605.5*	84	400.5	43	205.0
Congenital anomalies (Congenital malformations, deformations, and chromosomal abnormalities)***	39	186.0	29	138.3	10	47.7
Influenza and pneumonia	1	.8	1	4.8	-	-
<b>Conditions Originating in the Perinatal Period</b>						
Other conditions originating in perinatal period	21	100.1	20	100.1	-	-
Disorders related to short gestation and unspecified LBW	12	57.2	12	57.2	-	-
Newborn affected by maternal complications of pregnancy	8	38.1	8	38.1	1	4.8
Newborn affected by complications of placenta, cord, and membranes	5	23.8	5	23.8		
Respiratory distress of newborn	3	14.3	3	14.3	-	-
Intrauterine hypoxia and birth asphyxia	2	9.5	2	9.5		
Infections specific to the perinatal period	2	9.5	2	9.5	-	-
<b>Deaths Reported as SIDS</b>						
	13	62.0	-	-	13	62.0
<b>Death Due to Other Causes</b>						
	23	109.7	4	19.1	19	90.6

\*Per 100,000 live births

\*\* Data by cause of death based on ICD-10 codes

Source: IDHW Bureau of Health Policy and Vital Statistics, 2004

In Idaho, the preponderance of infant deaths occurs in the neonatal rather than the postneonatal period. As described previously neonatal and postneonatal mortality are examined differently as the primary prevention opportunities differ in accordance with the period in which the death occurred. For example, VLBW-related deaths can best be prevented by addressing maternal health issues and by preventing and treating prematurity. Neonatal deaths can best be prevented by providing optimal newborn care and postneonatal deaths by improving infant care.

The data reveal that congenital malformations (an abnormality present at birth); preterm and LBW births; complications of pregnancy; and complications affecting the newborn related to placenta, cord, and membranes are the major causes of infant death in the neonatal period. The most significant cause of death in the postneonatal period is reported by the State as SIDS.

SIDS is defined as the sudden death of an infant under 1 year of age that remains unexplained after a thorough case investigation. Although the SIDS designation is used in Idaho to describe several infant deaths, by definition a death can be designated as SIDS only following a thorough case investigation (National Vaccine Program Office, 2001), and this does not appear to be the case in Idaho.

Several recommendations regarding SIDS were included in the 1998 and 2000 reports of the Child Mortality Review Team, which existed at the time but has subsequently disbanded. Recommendations of the Team included the use of a SIDS investigation protocol to promote the further understanding of SIDS comprised of a thorough case investigation, autopsy (not required in Idaho), review of clinical history, and examination of the death scene to all children with presumptive diagnosis of SIDS, such as recommended by the CDC (Idaho Child Mortality Review Team, 2003). The Idaho Code requires that the county coroner, who is an elected county official, is charged with the investigation of the facts surrounding the cause and manner of death and has the authority to summon a person licensed to practice medicine in the State to help determine the cause of death and, if needed, to order an autopsy.

The Child Mortality Review Team indicated that 8 of the 11 SIDS-designated deaths in 2000 may have been preventable through the elimination of risks such as the infant being put down for sleep on their stomach, secondary tobacco exposure, and cosleeping (Idaho Child Mortality Review Team, 2003). The Review Team cited significant problems in obtaining data and reported that most SIDS-designated deaths did not have a SIDS investigation form completed and information was often missing.

In 2002, an additional 23 infant deaths were reported as “all other causes (residual)” (Idaho Department of Health and Welfare, 2004a). It would be useful to know more about the circumstances of these deaths. Comprehensive information about the cause of death permits the exploration of possibilities for the prevention of deaths.

Although the focus of this section is on infants, the problem of fetal deaths must also be considered, since fetal deaths account for a large proportion of pregnancy losses and therefore health promotion and interventions intended to improve pregnancy outcomes must also be considered. A fetal death is defined as an involuntary loss in which the fetus showed no evidence of life on delivery. Data that not only identify the number and timing of fetal deaths but that also describe the life style and medical risk factors of the pregnant women experiencing a fetal death are important to an understanding of this public health problem and how to address it. States often use a Fetal-Infant Mortality Review Team, similar to the Child Death Review Idaho used in previous years but no longer, to examine the causes of these deaths and to develop prevention activities subsequently.

According to the CDC, fetal deaths at under 20 weeks’ gestation account for 49 percent of all deaths that occur between the 20<sup>th</sup> week of pregnancy and the 1<sup>st</sup> year of life (Barfield et al., 2004). One of the Healthy People 2010 health objectives is to reduce deaths among fetuses of 20 weeks’ gestation or less to 4.1 deaths per 1,000 live births for all racial and ethnic population groups (U.S. Department of Health and Human Services, 2000). While there are inherent difficulties in collecting data on fetal deaths that contribute to an understanding of incidence and

the factors associated with these deaths, these data can provide information important to efforts to improve pregnancy outcomes. While the number of stillborn births is identified in Idaho, the State does not report data on fetal deaths occurring in the State.

**a. Newborn Metabolic Screening**

Idaho law requires that all babies born in the state receive a screening test for metabolic disorders that can result in mental retardation and/or other serious health problems. Idaho is a member of the Northwest Regional Newborn Screening Program and, through contract with the Oregon Public Health Laboratory, uses tandem mass spectrometry (MS/MS) technology to test for more than 30 conditions. The central screening laboratory and its follow-up team, working together with BOCAPS newborn screening staff, have developed a quality control program include ongoing education for practitioners with their screening practices. Components of the program include ongoing education assist practitioners and parents, computerized monitoring of certain screening practices, and an examination of communication channels between practitioners, the laboratory, and the follow-up team.

Reportable conditions screened for in Idaho include the following:

<b>Table VI-12. Reportable Idaho Newborn Screening Conditions</b>	
Phenylketonuria (PKU)	Biotinidase Deficiency
Congenital Hypothyroidism	Galactosemia
Maple Syrup Urine Disease	

Source: National Newborn Screening and Genetics Resource Center, 2005

BOCAPS staff have conducted training with staff from almost 30 birthing facilities across the State to promote the appropriate collection of blood specimens and the timely mailing of them to the Oregon laboratory. During the past year, this effort has significantly reduced the State's collective transit time errors to the laboratory. Instructional videos about specimen collection, purchased with Title V funds, have been provided free of charge to more than 20 of the largest birthing facilities in Idaho and to the lending library of the State's largest medical center.

Screening test kits are sold to Idaho practitioners through the State newborn screening office, and revenues from those sales cover the cost of the program with the exception of BOCAPS staff, who are funded through the Title V block grant.

The Idaho Chapter of the March of Dimes has organized a task force to examine newborn screening issues that involves State newborn screening staff, the Division of Medicaid, Blue Cross and Blue Shield medical directors, and the Idaho Hospital Association. This group is focusing on the development of newborn screening protocols and creative funding strategies to cover the high costs of formula required by individuals with PKU.

<b>Table VI-13.</b> <b>Number of Idaho Newborns Screened for Metabolic Conditions, Percent of Second Screens Performed and Number of Positive Results, 2002-2003</b>		
	<b>FY 2002</b>	<b>FY 2003</b>
Total number of births	20,970	21,802*
Number of screens performed**	20,404	21,174
Percent of 2 <sup>nd</sup> screens performed	72.4	76
Number of positives	12	23

\* 2003 preliminary data (Hamilton et al., 2004)

\*\*Evidence suggests that much of the difference between total number of births and number of screens performed may be due to a variety of birth certificate errors.

Source: Idaho Department of Health and Welfare, 2005

## **b. Newborn Hearing Screening**

The Joint Committee on Infant Hearing (JCIH) has established five benchmarks for newborn hearing screening; these include the percentage of infants screened, percentage referred, percentage rescreened, percentage rescreened who are referred, and percentage of those referred who receive follow-up (Joint Committee on Infant Hearing, 2000). In Idaho, the Council for the Deaf and Hard of Hearing is the recipient of the Early Hearing Detection and Intervention (*Idaho Sound Beginnings*) Project, awarded by the Idaho Department of Health and Welfare, and is responsible for the collection and regular reporting of data from Idaho hospitals on newborn screening activities. The following is a summary of newborn hearing screening activities for the years 2001-2003.

<b>Table VI-14.</b> <b>Newborn Screening Activity 2001-2002</b>			
	<b>2001</b>	<b>2002</b>	<b>2003</b>
# of hospitals reporting	27	31	34
Total ID hospital births reported	14,260	18,886	20,060
% inpatient hospital screens	96	97	97
% referred	16	14	10
% of screenings followed up	74	68	54
# of infants not returning for rescreen	891	883	1042
% with diagnostic follow-up	56	70	100
# of infants confirmed with hearing loss	48	33	31

Source: Idaho Council for the Deaf and Hard-of-Hearing, 2004

The Council for the Deaf and Hard-of-Hearing reports that the 34 of 35 hospitals are participating and over 97 percent of Idaho's babies are born where hearing screening is performed. Newborn hearing screening is not mandated in Idaho (Idaho Council for the Deaf and Hard-of-Hearing, 2004).

The JCIH benchmarks are used to assess hospital newborn screening activities; as reported for the first 6 months of 2004, 7 Idaho hospitals exceeded the JCIH benchmarks, 15 were below 1 benchmark, 10 below 2 benchmarks, and 1 below 3 benchmarks. These are all improvements from data reported for 2003. Fourth-quarter data for 2004 indicates that the percentage of infants returning for the second screening continues to increase (Idaho Council for the Deaf and Hard-of-Hearing, 2004).

As noted earlier, not all births in Idaho occur in hospitals. In 2002, 145 infants were born in a birthing facility and 351 born at home (Idaho Department of Health and Vital Statistics, 2004a). Out-of-hospital birthing facilities make various arrangements for newborn screening. Families may also take their infants to the Infant-Toddler Program for free screening. The Council reports working with the birthing centers, midwives, and childbirth educators to inform parents of the importance of newborn hearing screening and the resources available to obtain the screening.

The hospital performing the initial screen notifies the Council of infants requiring a follow-up screen who have not been brought for the screen within 1 month. The Council follows up with the family and refers them to the Infant-Toddler Program. Infants with a confirmed hearing loss are enrolled in the Infant-Toddler Program, which then works with the family to establish a medical home for the infant. The Infant-Toddler Program coordinates with the Idaho School for the Deaf and Blind, which works with children ages 0-21 and their families around an array of issues related to the hearing loss. The Council reported an overall 97 percent newborn hearing screening rate for hospital births in Idaho in 2003 (Idaho Council for the Deaf and Hard-of-Hearing, 2004).

While significant progress is being made in the State with newborn hearing screening and follow-up, several issues remain as reported by key informants. These include improving overall screening rates and the management of newborn screening for infants not born in a hospital, strengthening follow-up of infants requiring repeat screens and diagnostic follow-up, bringing all hospitals into compliance with JCIH benchmarks, and assisting families with the acquisition of hearing aids for their infant or toddler with hearing loss

### **3. *VLBW or preterm babies are born in facilities equipped to care for them.***

The availability of neonatal intensive care has improved outcomes for high-risk infants including those born preterm or with serious medical or surgical conditions. The concept of regionalized perinatal care was articulated in the 1976 March of Dimes report *Toward Improving the Outcome of Pregnancy* and endorsed in the American College of Obstetricians and Gynecologists (ACOG) guidelines (Committee on Perinatal Health, 1976). The March of Dimes report included criteria that stratified maternal and neonatal care into three levels of complexity and recommended referral of high-risk patients to centers with the personnel and resources needed for their degree of risk and severity of illness.

The establishment of uniform definitions of levels of care offers many advantages that may improve infant outcomes and provide the basis for policy decisions that affect allocation of resources. Standard definitions permit policy and program comparisons, help consumers to understand health care options, and, most importantly, facilitate the development and

implementation of consistent standards of service provided at each level. The appropriate matching of levels of complexity of neonatal care to patient needs requires recognition of risk factors. Most studies that link neonatal outcomes with levels of perinatal care indicate that morbidity and mortality for VLBW infants are improved when delivery occurs in a subspecialty facility rather than a basic facility. Since transfer of the infant can negatively impact neonatal outcomes, it is important, to the extent possible, that high-risk infants are delivered in a facility capable of providing the anticipated appropriate level of neonatal intensive care unite (NICU) care (Committee on Fetus and Newborn, 2004).

The following are definitions of levels of neonatal intensive care recommended by the American Academy of Pediatrics:

- **Level I (basic):** A hospital nursery organized with the personnel and equipment to evaluate and provide postnatal care of healthy newborn infants, stabilize infants born at 35 to 37 weeks' gestation and provide care for those who remain stable, and stabilize infants born at less that 35 weeks' gestational age or ill until transfer to a facility who can provide the appropriate level of care.
- **Level II (specialty):** A hospital special care nursery organized with the personnel and equipment to provide care to infants born at more than 32 weeks' gestation and weighing more than 1,500 grams who have physiologic immaturity or are moderately ill with problems that are expected to resolve rapidly.
- **Level III (subspecialty):** A hospital NICU organized with the personnel and equipment to provide continuous life support and comprehensive care for extremely high-risk newborns and those with complex and critical illnesses (Committee on Fetus and Newborn, 2004).

The Idaho Hospital Association identified the hospitals with NICUs, and then each hospital was surveyed to learn how the hospital designates the level of neonatal care provided. Table VI-15 displays the responses of the hospitals.

<b>Table VI-15. Idaho NICUs by Level</b>		
<b>Hospital</b>	<b>Location</b>	<b>Level</b>
Eastern Idaho Regional Medical Center	Idaho Falls, Bonneville County	Level II
Magic Valley Regional Medical Center	Twin Falls, Twin Falls County	Level III
Portneuf Medical Center	Pocatello, Bannock County	Level II
Saint Alphonsus Regional Medical Center	Boise, Ada County	Level II
St. Joseph Regional Medical Center	Lewiston, Nez Perce County	Level III
St. Luke's Medical Center	Boise, Bannock County	Level III

Source: Hospital Telephone Survey, 2004

### ***What Do Parents Say About Their NICU experiences?***

*Parents in the Pocatello, Orofino, and Bonner's Ferry area focus groups described varied experiences in how complications were handled by hospitals. A common complaint expressed was the lack of information provided to parents about the care provided to their babies while in the NICU. The social workers associated with the NICUs got mixed reviews, with some reported as helpful and others not. Some parents particularly complained about their hospital experiences around the birth of premature babies, saying that the health care professionals did not listen to their concerns because they were first-time mothers. Others, however, said they were provided with the information they needed and especially appreciated the follow-up calls they received from the hospital because their baby was premature.*

While the Idaho Administrative Code, Standards for Hospitals in Idaho Section 400 Maternity and Newborn Service identifies requirements for basic newborn care, it does not make mention of requirements for neonatal intensive care. It does, however, require that hospitals have a policy for types of high-risk mothers and infants admitted and policy and procedure for consultation with and/or transfer to a NICU for high-risk infants (Idaho Administrative Code 16.03.14). This suggests that the hospitals have the capability to collect information about the admissions of high-risk mothers and infants that could be useful to a better understanding of the nature of the risk and the characteristics of the mothers and infants. This, in turn, would be helpful in assuring the availability of risk-appropriate care.

While Idaho reported in the States' 2004 Title V Block Grant application that 72.8 percent of VLBW or preterm infants were born in a facility equipped to care for them on 2003, information was not available about the source of the 2003 data. Data for 2004 was also not available. The Bureau of Vital Statistics indicated that this information could not be obtained from the hospitals due to confidentiality issues. Consequently, due to the lack of access to hospital data, the hospital locations and levels of NICU care provided to these infants are unknown. Also unknown are the number of VLBW or preterm infants born at each facility, the number of these infants who were transferred into each facility, and the characteristics of mothers giving birth to these high-risk infants. This information would be invaluable in assessing the effectiveness of regionalization and how it could be further strengthened to promote positive births outcomes. Matching the risk of the mother and/or infant with a facility that has the ability to manage their care adequately goes a long way to decreasing immediate and long-term complications and costs. Regionalization of perinatal care has repeatedly been demonstrated to decrease the mortality and morbidity of high-risk infants (McCormick et al, 1985; Cooke, 1987).

Idaho PRATS data does provide some data about experiences of parents with infants admitted to a neonatal intensive care nursery following delivery. Overall, 9.0 percent of Idaho resident adult mothers responding to the 1999 PRATS survey reported that their new baby was placed in a NICU after delivery (Idaho Department of Health and Welfare, 2001). The majority of these infants were placed in a NICU at the same facility where the delivery occurred. Only about one in four mothers whose baby was admitted to a NICU was told about community support programs like the Infant-Toddler Program or the Children's Special Health Program.



**3. *Infants are welcomed into a family, a home, and a community that is prepared to care for them.***

Families are reconfigured at the birth of their first child and continue to readjust as a family unit with each succeeding birth. Parents and other family members are the most important people in the lives of infants and have the primary responsibility for guiding their children to healthy, productive, and satisfying adulthood. In this most important of all roles, families need access to an array of community resources to nurture their infants in a loving, safe, and secure environment. In short, parents need to provide a roof over the heads of their families, put food on the table, and get their young children ready for life. Economic, housing, food, and health care access security are all factors that directly impact health status and must be a part of every discussion about maternal, child, and family health.

The preceding section of the report contains a detailed description of family security needs. A family prepared to welcome an infant is one that is economically secure, has access to adequate housing and food, and can obtain health care for all its members. Family security is tied to the ability of the community to provide employment that offers families a living wage, housing stock that is safe and affordable, access to nutritious food, and a health care system that is responsive to the needs of families. In addition, families need access to systems and services in their community that can provide them with information, education, and support needed to sustain the family unit and promote the health and well-being of its members.

***What Do Parents Say?***

*Mothers in the Pocatello, Orofino, and Bonner's Ferry areas talked about their experiences following the birth of their babies. A common theme expressed by these mothers was the lack of information they were provided regarding what to expect after the delivery of their baby. While they cited several activities that were helpful, including receiving brochures and some training such as baby CPR from the hospital and some access to lactation specialists, overall the mothers wanted more.*

Parents participating in the Idaho Family Survey indicated a need for assistance around feeling overwhelmed by the birth of their baby and for their feelings of sadness or depression. Of the 460 parents who responded to a question about “feeling overwhelmed,” almost 23 percent reported needing help in this area but being unable to find and use assistance that was helpful. Responses to a similar question about feeling “sad, blue, or depressed” revealed that 19 percent of the parents needed help with these feelings but were unable to find and use help that was useful to them. Another 19 percent of respondents indicated needing someone to care for their infant while they were at work or school and being unable to find and use help.

There are several community-based programs in Idaho designed to prepare families for the arrival of their infants and to support them in their role as parents. Several examples are provided below.

## a. Parents as Teachers Program

PAT is a voluntary program offered free to any expectant parent or those with children newborn to 5 years of age. The University of Idaho PAT Demonstration Project reports that the 48 PAT programs located in the State provided services to over 1,575 families and 2200 children in 2004 (Idaho Parents as Teachers, 2004). In 1999, at the request of the Governor, 13 of these sites were initiated as demonstration projects to permit a comprehensive assessment and evaluation of PAT. The program provides parents with the information and support they need to give their child the best possible start in life. The program is based on the philosophy that parents are their children's first and most influential teachers. PAT uses the Born to Learn curriculum that translates information on early brain development into concrete, "when, what, how, and why" advice for families.

A survey of parents enrolled in the 13 demonstration sites from 2001-2004 was conducted by the University of Idaho PAT program to assess program outcomes. Program activities and outcomes from the survey reported in 2004 include:

- **Home Visits.** The personal home visit offer parents personal time, one on one, in which information about child development and child rearing information is shared and a partnership formed between the parent and the trained parent educator.
  - *Ninety-five (95) percent of parents rated the personal visits as very helpful.*
- **Parent Involvement.** Educators demonstrate an activity and then get the parent involved in trying the activities with their child. Parents then repeat these activities with their child and as a result increase their ability to identify their child's needs and respond effectively.
  - *Eighty-five (85) percent of families use the PAT follow-up activities more than half the time.*
- **Group Meetings.** Monthly group meetings of PAT families allows parents to learn from each other, share common experiences and concern, develop lasting friendships, and form new support networks.
  - *Parents report their connections to other families increased as a result of PAT.*
- **Screenings.** Regular developmental screenings can expose potential problem areas which may inhibit learning. This screening provides parents with information and guidance about their child's development and emerging skills. When an educator and a parent identify a concern, an appropriate referral is made and the family is supported in addressing the need.
  - *A total of 1,693 children were screened for development, hearing, and vision.*

- ***Literacy Development.*** Research in literacy shows that the foundations of literacy are laid well before children come to school. The PAT Program helps parents develop strategies to help their children learn in the early years.
  - *Parents in PAT significantly increased the amount they read to their children (Idaho Parents as Teachers, 2004).*

## **b. Children's Trust Fund**

The Idaho Children's Trust Fund was established by an act of the State legislature in 1985 to promote child and family well-being in the State of Idaho in the belief that the best way to prevent child abuse and neglect is to support families and provide parents with the skills and resources they need to raise healthy children. The Trust Fund makes grants and provides training and technical assistance to programs throughout the State that work directly with children and their families. While located within State government, the Trust Fund is a unique public-private partnership that receives no State general funds and is supported by private citizens who raise funds for community grants.

For the fiscal year 2004-2005, 22 communities received funds to support families (Idaho Children's Trust Fund, 2004). These programs included a focus on assuring prenatal care for pregnant women, providing education and support for new moms, and organizing and conducting parenting classes for both mothers and fathers. Health District I conducts a program targeted to parents of infants born prematurely and/or who are medically fragile or developmentally delayed. The Trust Fund emphasizes outcome accountability and defines this as "identifying the positive changes that are expected for participants in programs, measuring the extent to which these changes did or did not occur" (Idaho Children's Trust Fund, 2004).

Examples of Trust Fund-sponsored outcomes include:

- ***ICARE, Inc.*** Coeur d'Alene provided Love and Logic parenting classes to 336 parents who reported feeling less stressed and more competent in managing discipline as a result of participation in the classes.
- ***The High Risk Infant/Toddler Project***, managed by the Panhandle Health District in northern Idaho, reported that 155 parents who received services via home visits indicated increased knowledge of child development, parenting skills, and ways to reduce family stress (Idaho Children's Trust Fund, 2004).

## **c. Parents Encouraging Parents (PEP)**

PEP is a nonprofit organization with a mission of promoting the health of families in all aspects (physical, mental, social, and emotional), strengthening family structures, and increasing parenting skills (Parents Encouraging Parents, 2004). Both online and community-based parenting classes are offered across the State. Data about participation and program outcomes are not available.

#### **d. Community Family Support and Education Programs**

An array of family-focused programs is available in a variety of communities across the state with some sponsored by hospitals, nonprofit agencies, and the faith community. They provide services ranging from warmlines to obtain information and guidance about parenting issues to the conduct of educational and counseling programs. Several of the agencies also offer assistance to promote family security in relation to income, housing, food, and access to health care. Many of these programs are included in the Idaho CareLine database. Data about family participation and program outcomes are not available.

It should be noted that while some areas, like Boise, have a number of family support and education programs available, other areas have very limited access to these programs.

#### **4. *Infants appropriately receive ongoing comprehensive preventive and primary care***

Since the number of infants and children in the State eligible for Medicaid is not available by age, the number of infants eligible for the program and the ratio of those eligible to those enrolled in Medicaid and EPSDT are not known. The primary discussion of the overall Medicaid program is included in the Infrastructure Section of this document. Briefly, the EPSDT service is Medicaid's comprehensive and preventive child health program for individuals under the age of 21. The purpose of the program is to meet the health needs of children through the conduct of initial and periodic health examinations and evaluations and to assure that the health problems found are diagnosed and treated early, before they become more complex. EPSDT covers medically necessary diagnostic and treatment services to address conditions or illnesses identified via the screening activities.

Infants should have well-child (EPSDT) checkups at:

- Under 1 month
- 2 months
- 4 months
- 6 months
- 9 months
- 12 months.

These checkups should include a comprehensive health and developmental history, a developmental assessment, a comprehensive unclothed physical examination, appropriate immunizations, laboratory tests appropriate for age and risk factors, and health education and anticipatory guidance for the infant's parents or caretakers.

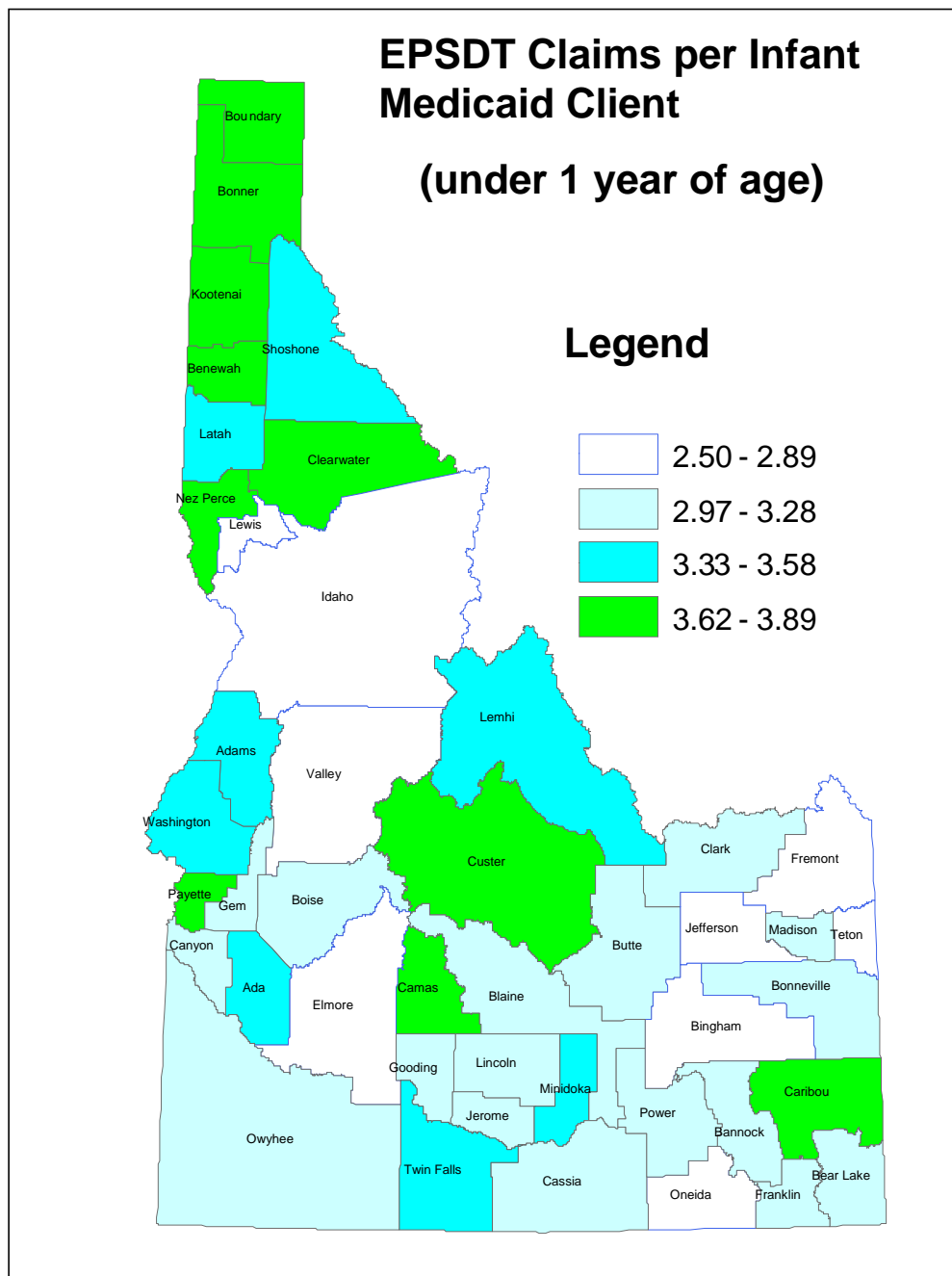
Table VI-16 displays the number of infants (under 1 year of age) enrolled in the Idaho EPSDT Program and screenings reported during the period October 1, 2002, to September 30, 2003.

<b>Table VI-16. Annual EPSDT Participation Report – Idaho 10/02-9/03</b>	
<b>EPSDT</b>	<b>Number of Children Less than 1 Year Old</b>
Number of eligible infants	10,835
Total eligible infants receiving at least one screening	6,019
Expected number of screenings per eligible Infant	3.15
Expected number of initial or periodic screening services	34,130
Actual number of initial or periodic screening services	16,452
Total number of eligible infants referred for corrective treatment	0
Total eligible infants enrolled in managed care	5,203
Total number of screening blood lead tests	12

Source: Centers for Medicare & Medicaid, 2005

With almost 50 percent of the infants reported as enrolled in managed care (Centers for Medicare & Medicaid, 2005), it would appear that there may be opportunities to increase the number of screenings, although it is not clear from the data what percentage of the screenings are attributed to infants enrolled in managed care.

As displayed on the Figure IV-11, which shows EPSDT claims per client among infants enrolled in Medicaid during 2003, the highest rate of utilization of EPSDT occurs in the northern counties, two central Idaho counties, and the population centers in the southern section of the State. Overall, it appears that a significant number of infants eligible for EPSDT visits are not obtaining the services they need. There may be data issues related to EPSDT reporting, as surely more than two infants were referred for treatment following an EPSDT screen.



**Figure VI-11: EPSDT Claims per Infant Medicaid Client**

Source: Idaho Medicaid Office, 2004

The EPSDT or well-child visit presents an opportunity not only to assess the health and development of the infant but to address the concerns of the infant's parents. Several key informants indicated during interviews that developmental screening of infants by physicians other than pediatricians is not standard practice.

Another opportunity for screening available to parents who have delivered a newborn in a hospital setting is a tool designed to help them understand their infant and toddler's

development. Parents return the completed tool to the DHO who then review them and forward surveys to the ZERO TO THREE Program for follow-up when a concern is raised about the infants' growth and development. In 2003, 5,500 tools were sent to new parents.

Responses to the Idaho Family Survey revealed that almost 57 percent of families surveyed reported that they did not need help finding a health care provider for their infant. Another 39 percent indicated that they had needed assistance locating a provider and had been able to use successfully the information they found.

The PRATS, described under the previous set of outcomes, also includes information about preventive care for infants.

<b>Table VI-17. PRATS Survey Responses – Infant Preventive Care</b>			
<b>PRATS question:</b>	<b>1999 Yes</b>	<b>2001 Yes</b>	<b>Comments</b>
<b>Used car seat bringing infant home from hospital?</b>	98.5%	99.4%	Does not reveal if car seats properly installed or in ongoing use.
<b>Place infant on back to sleep?</b>	63.2 %	68.1%	Although in 1999 63.2% reported doing this “most of the time,” an additional 8.4% reported placing the infant on his/her back “much of the time.” The reported rate for back to sleep increased in 2001.
<b>Infant exposed to secondhand tobacco?</b>	3.3%	7.7%	In 1999, only 3.3 percent of mothers reported that their new baby had some daily exposure to environmental tobacco smoke. The reported rate more than doubled for 2001.
<b>Infant up to date with immunizations?</b>	89.5%	81.0%	Mothers who reported that they had not wanted to be pregnant then or at any time in the future were less likely to have their baby's immunizations up to date than mothers who had want to become pregnant. Mothers with babies not up to date with their infant's immunizations were asked to identify the reasons for this. One (1) out of 4 mothers indicated that they thought immunizations were not safe; another 22.3 percent indicated that they had too much going on, while an additional 13.4 percent indicated that they did not have enough money or insurance to pay for it. Ten (10) percent or less of mothers indicated that lack of transportation childcare, knowledge of where to go, and/or appointment availability prevented them from getting immunizations for their infant. Fewer than 20 mothers reported not understanding the immunization scheduled as the reason why they had not fully immunized their new baby.

Sources: 1999 data is from Idaho Department of Health and Welfare (2001) and 2005a

### ***What Do Parents Say?***

*Mothers in the focus groups conducted in Pocatello, Orofino, and Bonner's Ferry were asked about well baby visits; many indicated they skipped some of these because of the cost and took their baby instead to the local health department for immunizations.*

## **Parenting Education and Support**

Few events are as life changing as becoming a parent. This is also an event for which most first-time parents feel inadequately prepared. The need for more parenting education and support services was identified at each of the Early Childhood Early Learning Task Force regional meetings conducted across Idaho, indicating that the need for parenting education and support is a statewide issue. In these meetings, parents reported being faced with simultaneously financial issues; the responsibility of maintaining a home; and providing for the developmental, social, and emotional needs of their children. Mothers and fathers said they tend to parent the way they were parented because this is what they know but felt that they needed other guidance as well. Often, extended family is not available to support these parents and lend a hand when needed.

Support services also need to be available to grandparents who are raising their grandchildren. In 2000, there were 8,110 grandparents who reported they were responsible for their grandchildren (GrandsPlace, 2002). Two (2) percent of these grandparents are African American, 12 percent are Hispanic, 1 percent are Asian, 4 percent are American Indian or Alaskan Native, and 79 percent are White. Forty-three (43) percent of these grandparents live in households without the children's parents present. Over 700 of the grandparents live in the Boise area. In Idaho, there are 13,636 children living in grandparent-headed households; this represents 3.7 percent of all the children in the State.

Idaho has developed several kinship care programs to assist these grandparents and other nonparental caregivers. These include the Idaho Kincare Coalition, the Commission on Aging, the AARP State Office, the Cooperative Extension, and several other community-based groups.

The following is a summary and analysis of key findings.

## **Summary Findings and Analysis**

### **Idaho Infant Outcomes**

**Infants are born at term, of normal weight, without preventable congenital defects and are appropriately screened for potential problems.**

#### **Summary**

- While Idaho compares favorably with overall national data for birth outcomes, there are population groups with rates of premature and LBW births, birth defects, and infant mortality that are of concern. These problems generally occur in the most rural counties and those with higher numbers of Hispanic residents.
- There are an array of agencies, organizations, and stakeholders providing various



### Idaho Infant Outcomes

aspects of care to promote positive birth outcomes.

- There is insufficient data available regarding program utilization and outcomes.
- Important hospital data is not available.
- With the demise of the Child Mortality Review Team, infant deaths are not reviewed for preventable causes.
- A growing number of births are occurring outside of hospital settings.

#### Analysis

- Overall services and care appear fragmented, which reduces the effective use of existing resources. Continuity of risk-based perinatal care is important to the promotion of positive birth outcomes. It is important that the perinatal system also include prenatal, delivery, and follow-up care provided by midwives.
- The lack of meaningful outcome-focused program data is a barrier to assessing the effectiveness of activities, which results in lost opportunities to allocate resources to efforts that are effective.
- The state's neonatal and postneonatal death rates, as well as the infant mortality rates, provide guidance as to interventions needed to avoid these deaths. Understanding when deaths occur by examining perinatal periods of risk permits the appropriate focusing of interventions.
- Not all deaths attributed to SIDS appear to be comprehensively investigated using CDC guidelines and the causes of other infant deaths are not described in the available data. The investigation of infant deaths can be a very important public health tool that can lead to policies and interventions that will prevent future deaths.
- Idaho reports very high rates of deaths due to birth defects. The lack of a birth defects registry impedes the identification and tracking of infants and services and could be useful to an array of programs including newborn screening and child finding.

### **VLBW or preterm babies are born in facilities equipped to care for them.**

#### Summary

- When infants at risk are born in a facility prepared to care for them, birth outcomes improve. The lack of specific data indicating the overall rate and characteristics of these infants born in appropriate facilities significantly limits an assessment of the effectiveness of regionalization and access to the appropriate level of care for high risk infants.

#### Analysis

This lack of data limits the opportunity for a collaborative exploration of problems related to high risk births and the development of collective solutions. Important to the achievement of “data-driven” systems of care is the availability of data from all sectors of the system, including hospitals.

**Infants are welcomed into a family, a home, and a community that is prepared to care for them.**

### **Summary**

- Many working Idaho families are economically insecure and the extent of this insecurity varies greatly across the state.
- Idaho TANF monthly benefits are significantly lower than benefits in surrounding States.
- There are no TANI (Idaho TANF) work exceptions for parents caring for children with significant health or disabling conditions.
- A significant percentage of Idaho families are housing cost burdened forced to pay a high percent of their income to pay for housing.
- African Americans and Hispanics have disproportionate rates of homelessness.
- Migrant and seasonal workers are often at considerable risk for inadequate housing.
- In Idaho 13.7 percent of households (as compared national rate of 11 percent) are food insecure.
- Idaho ranks 28<sup>th</sup> of all the States in overall State food participation rates.
- Education and support programs are available in some sections of the State and accessible to some, but not all, parents.
- A significant number of parents indicate a need for emotional support and are unable to find assistance that is helpful to them.

### **Analysis**

- Adequate family income, housing and food are essential to a family's ability to care for their infants. The data suggests that many families are struggling to obtain access to basic needs; particularly in need or single mothers, migrant or seasonal workers, and Hispanic and African American families.
- Policies and programs related to any aspect of economic security, housing, and food availability should take into account their importance to MCH outcomes.
- The involvement of MCH stakeholders in policies and programs that focus on the economic, housing, food, and health care access security issues can promote collaboration on these issues.
- A number of agencies are focused on activities designed to strengthen families and community support, but these efforts appear fragmented at the State and local levels. There are no overarching family outcomes or program data collection methods in place.

## **Infants appropriately receive ongoing comprehensive preventive and primary care.**

### **Summary**

- A significant number of infants did not receive the prescribed number of EPSDT screens.
- No infants of the total screened were reported as referred for treatment.
- For infants as a group, limited data is available to assess the extent that they receive ongoing comprehensive preventive and primary care.
- The State does not recommend and subsequently promote a health supervision guide focused on comprehensive preventive and primary care.

### **Analysis**

- Limited data is available to provide information about the level of comprehensive preventive and primary care received by infants.
- While EPSDT is available to infants only when they are enrolled in Medicaid, it is a program that can assure that infants are screened for both health and developmental status and referred appropriately. This appears to be an underused opportunity in Idaho, with rates for infants in northern areas of the State higher than those for infants in other areas of the State. It would be useful to know the extent of screening for infants enrolled in managed care compared to those not enrolled in managed care.
- Without adequate data, it is difficult to know which infants are or are not receiving appropriate care. This lack of data prevents the development of appropriate strategies to promote ongoing care and a medical home.
- It is unclear what is being done in the state to promote adequate developmental screening of infants. These screenings are an important aspect of early care and education initiatives.
- The effectiveness of managed care in providing infants with a medical home is unclear.